

Beryllium Exposure Registry

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What is an Exposure Registry?

- **R**egistries evolved because of a need for fundamental information concerning the potential impact on human health of exposure to long-term, low and moderate levels of hazardous substances
 - Disease Based, e.g., Cancer, diabetes
 - Exposure Based e.g., REMS, beryllium
 - A system for collecting and maintaining in a structured record, information on persons with documented environmental exposure(s).

Registry Information Use

- Information in registries is used to identify rates of illness
- **DOE** maintains one of the largest registries in the world - the Radiation Exposure Registry - covering nearly 100,000 workers

Goals of a Beryllium Registry

- **T**o monitor the effectiveness of DOE's Chronic Beryllium Disease Prevention Program efforts by establishing and maintaining a registry of all beryllium-exposed workers and their ongoing health status as it relates to beryllium exposure
- **T**o track all beryllium workers regardless of the site or movement between sites

Goals of a Beryllium Registry

- “**W**atchful vigilance”
 - **T**o provide feedback of analyses of registry data to workers and health and safety professionals focusing on early warnings to guide timely intervention and prevention activities and to improve control measures as appropriate

Goals of a Beryllium Registry

- **T**o provide information that assesses the burden of the effects of beryllium exposure or health outcomes
- **T**o facilitate epidemiologic studies and health surveillance programs to better understand chronic beryllium disease and its prevention

Proposed Beryllium Rule

- **S**ites would establish and maintain accurate records including medical surveillance
- **R**ecords would be in electronic form
- **S**ites would link data sets on working conditions to health outcomes
- **S**ites would establish and maintain a separate beryllium registry to include all beryllium workers
- **S**ites would transmit registry data electronically, semi-annually to the Office of Epidemiologic Studies

Data Elements

- **N**ame
- **S**ocial Security Number
- **D**ate of Birth
- **G**ender
- **S**ite
- **J**ob History
- **M**edical Screening and Follow-Up Results

Recordkeeping

- **R**ecords contained in a Beryllium Registry are covered under the Privacy Act of 1974; use of records under this act is governed by specified routine uses
- **R**egistry information would be gathered pursuant to and contained within DOE Record System 88 “Epidemiologic and Other Studies, Surveys, and Surveillance”

Survey of Occ-Med Departments

- **26** sites identified
- **C**ontact made with 20 site occ-med departments
- **T**o date, identified approximately 2,600 exposed workers to be included in the initial registry
- **5** sites maintain medical records in some type of electronic format
- **S**ome sites are closed; some occ-med departments are closed; records are stored at other sites or in private occ-med organizations